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Exploring the barriers and gateways to intersubjectivity in dementia care: A meta-ethnography

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Abstract

Background: Behaviours that challenge in dementia, often described and diagnosed as behavioural psychological symptoms of dementia, are experienced by 75% of people living with dementia in care homes or hospital environments, with 43% of nurses and care providers reporting these behaviours as moderately or severely distressing to them. During behaviours that challenge moments in dementia, there is the potential for an intersubjective relationship to take place between the people living with dementia and the nurse.

Aims: This review explores and synthesises literature to consider the presence of intersubjectivity in people living with dementia. If the ability to be intersubjective remains present for people living with dementia, it will consider how its presence can be nurtured to offer a positive intersubjective communication between the person living with dementia and their carer/nurse.

Methods: The review used meta-ethnography methodology to develop concepts that help us to understand the implications of existing research on the presence of intersubjectivity in people living with dementia, and its relationship to those providing their care. Sixteen electronic databases (including MEDLINE/PubMed, Wiley Online Library and Sage publications) and grey literature such as Alzheimer's Society and Department of Health across journals dating from 2000–2020 were searched. Eight studies were selected and reviewed for quality and relevance for a meta-ethnographic literature synthesis of intersubjectivity in dementia.

Conclusion: The meta-ethnography concluded that people living with dementia continue to have the capacity to be intersubjective on an emotional level. Nurses and other care providers need to acknowledge the presence of “personhood” and “personness” in people living with dementia to nurture positive intersubjective care relationships. The meta-ethnography has also been reviewed for reporting clarity against the EQUATOR checklist in the form of the eMERGe guideline (France et al., 2019).

The work for this literature review was completed with Lancaster University. However, the first/corresponding author was based in University Plymouth at the time of submission.

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KEYWORDS

care, communication, dementia, interpersonal communication, meta-synthesis, models of care, nurses, nursing, patients' experience, therapeutic relationships

1 | INTRODUCTION

1.1 | Introducing intersubjectivity

Intersubjectivity is described as a shared emotional, linguistic, perceptual or cognitive meaning or understanding of any given situation via a transfer of energy between two or more subjects (Decety & Lamm, 2009). It is, however, a subject which can create debate due to it being grounded in two polarised paradigms: first, a traditional objective (positivist) perspective, and second, a humanistic subjective (constructivist) perspective (Di Paolo & De Jaegher, 2015). This paradigmatic perceptual argument is not one that only takes place in research, but also in nursing practice and healthcare provision. Jeffrey (2016) argued that as a consequence of this paradigmatic argument, nursing care moved from being subjective-focused care, towards an objective, mechanistic, diagnostic, problem-focused and dehumanised care provision. Fabian (2014), however, argues that social sciences, mainly in the form of phenomenology, have now taken away the control and ownership of subjectivity from the quantitative paradigm and placed it back within an experiential and qualitative intersubjective/subjective narrative.

This shift in paradigm led to a new focus in nursing towards consultation and collaboration through human interaction and empathy (Bickerton, Procter, Johnson, & Medina, 2011). Although care providers must be mindful that even though this humanised approach to dementia care is admirable, it can also become a "fallacy of care" (Leibing, 2019 p.6) if the love and compassion provided hide poor practice or treatment gaps. During intersubjective moments, there is always a balance to be struck between meeting a task-orientated need of the person living with dementia and their need for human connection, a place where patient needs are recognised as a human need (Hansen, Hauge, & Bergland, 2017). In a moment where the subjective "I" moves to a position of an intersubjective "us"; a place where "world-experience is not a private experience it is shared experience" (Schutz, 1966 p.54).

2 | RATIONALE FOR META-ETHNOGRAPHY

Behaviours that challenge in dementia, often described and diagnosed as behavioural psychological symptoms of dementia, are experienced by 75% people living with dementia in care homes or hospital environments (White et al., 2016), with 43% of nurses and care providers reporting these behaviours as moderately or severely distressing to them (Sampson et al., 2014). However, it must be acknowledged that these moments of challenge are not just distressing nurses caring for them, but also the person living with dementia due to the negative impact on their quality of life.

What does this paper contribute to the wider global clinical community?

- Confirms that people with dementia maintain emotional intersubjectivity.
- Offers a person centred and individual model of dementia care.
- Highlights the need for 'personhood' and 'personness' in dementia care.

This aspect of dementia care has become controversial, particularly as these moments are often "managed" by using medication, with 55% of people presenting with disruptive behaviours typically receiving psychotropics, mainly in the form of antipsychotics (White et al., 2016). Yet, only 10% are reported to actually receive the correct pharmaceutical treatment (Van der Spek et al., 2016). These treatment decisions place the person living with dementia at risk of cerebral vascular decline, a deterioration in their cognition and, at times, even early death (Tampi, Tampi, Balachandran, & Srinivasan, 2017). Mortality was particularly prevalent in those being treated with high-dose haloperidol (Hui, Wong, & Wijesinghe, 2016) and those with comorbid health conditions (Kheirbek et al., 2019). As well as the risks associated with psychotropic treatments, there is also a risk that this treatment intervention becomes the default position when a person living with dementia presents with behaviours that challenge. Such a position offers very little in terms of understanding the biopsychosocial factors behind the presenting behaviour in order to support future (interventions/treatment) decision-making.

There are of course alternative support options for people living with dementia who present with behaviours that challenge, and these include several nonpharmacological interventions (Abraham et al., 2017). However, these interventions are somewhat reliant on nurses and care providers intervening with tailored and individualised care to meet the person's needs, which requires planning, time and a desire to provide alternative approaches (Ijaopo, 2017). This is in a culture where many nurses are citing a lack of time, resources and staff to provide nonpharmacological or person-centred care (Ross, Tod, & Clarke, 2014).

Sorroza Lopez and Martino-Roaro (2016) acknowledged that nonpharmacological behavioural interventions cost nearly £27.6 million more than using antipsychotic drugs. However, it has been estimated for every pound invested in nonpharmacological behavioural interventions; nearly two pounds could be saved in health costs and quality-of-life outcomes (NHS Institute for Innovation &

Improvement, 2011). When measuring quality-of-life outcomes alone, the use of nonpharmacological behavioural interventions rather than antipsychotics for the treatment of behaviours that challenge would lead to an estimated saving of £54.9 million per year in England alone (NHS Institute for Innovation & Improvement, 2011). These person-centred and individualised nurse-led interventions not only have a potential financial cost saving, but perhaps more importantly have a significant impact on the person living with dementia's quality of life and well-being (Breachin, Murphy, James, & Codner, 2013).

If mutual respect is delivered as an integral component of all care, even in times of resource austerity (Kerasidou, 2019) there is no reason why person-centred care moments should not exist. One way of acknowledging these moments is to always recognise the person living with dementia's "personhood" (Kitwood, 1997, p.8). Kitwood (1997, p.8) describes personhood as "a position or social relationship that is bestowed on one human being by others, in the context of relationship and social being." However, to consider and explore this interrelationship between the nurse and the person living with dementia requires an understanding of the role of intersubjectivity in these care relationships. This meta-ethnography literature review and synthesis therefore seeks to answer the question of what is intersubjectivity for a person living with dementia? Once this is established, there are opportunities to create constructs to better explore, explain and encourage positive intersubjectivity in dementia care.

The literature review and synthesis aims to:

1. Explore if the ability to be intersubjective remains present in people living with dementia.
2. If the ability to be intersubjective remains present for people living with dementia, how does it present, and how can it be nurtured positively?

3 | METHOD

In order to explore the presence of intersubjectivity, and how it can be nurtured positively for people living with dementia, a

seven-stage meta-ethnography literature review and synthesis was completed (Noblit & Hare, 1988). Table 1 is an explanation of Noblit and Hare's (1988) seven stages of the model which will be used as subheadings in this literature review/synthesis, alongside conventional style headings. The meta-ethnography has also been reviewed for reporting clarity against the EQUATOR checklist in the form of the meta-ethnography reporting guidance (eMERGe) (France et al., 2019) (File S1).

The following meta-ethnography uses a synthesis of qualitative literature to consider and analyse intersubjectivity by describing and reflecting on any inter-relational and interpersonal dialogical, perceptual or emotional connection between people living with dementia and others who provide their care, either formally or informally (including nurses). The method of literature and synthesis review chosen (meta-ethnography) provides and respects a qualitative, interpretive and inductive process and therefore is appropriate to explore the presence of intersubjectivity for people living with dementia through a synthesis of qualitative studies.

As well as exploring the presence of intersubjectivity in dementia the meta-ethnography also offers the opportunity to create testable hypotheses in the form of third-order constructs and interpretations (Britten et al., 2002). This is achieved by first capturing the words used by the participants in the selected studies; these are first-order constructs. However, these first-order constructs are only for information and synthesis initiation purposes and are not data interpretation, unlike the subsequent second-order constructs (Carey, Kent, & Latour, 2019). Second-order constructs are created by the assembling of the researcher/s data interpretation. These are reported as the findings of the author/s of the selected studies. These are then interpreted into third-order constructs and then developed into a thematic synthesis or the building of a story (Lachal, Revah-Levy, Orri, & Moro, 2017). Finally, a line of argument moves the data from the descriptive to the conceptual (Atkins et al., 2008). Although this process is completed in its entirety in this review, it is for the purpose of social or phenomenon explanation only (Brannelly, 2011) and not to develop a hypothesis to test within a future study.

TABLE 1 Noblit and Hare's (1988) seven stages of meta-ethnography examples

Seven stages	Synthesis stage	Example in study
Getting started	The need for an appropriate literature synthesis "Making sense"—terminology and search terms	Tables 2 and 3
Deciding what is relevant to the initial interest	Inclusion and Exclusion Criteria and PRISMA—"Focusing the topic."	Figure 1 and Table 4
Reading the studies	Reading/rereading—"Finding characteristics," quality and data extraction.	Tables 5 and 6
Determining how the studies are related	Highlighting areas of studies (Highlighting Pen in MS Word) and "1st order construct development."	Table 7
Translating the studies into one another	Continuation and repetition of above—"2nd order construct development."	Table 7
Synthesising translations	Interpretation and translation—"3rd order construct development."	Table 7
Expressing the synthesis	"Line-of-argument synthesis development."	Figure 2

TABLE 2 SPIDER search framework

S	Sample	People living with dementia/care providers
PI	Phenomenon of Interest	Presence of and factors associated with intersubjectivity in dementia
D	Design	Exploratory, experiential, phenomenology, social and interpretative
E	Evaluation	Narratives of intersubjective/inter-relational/interpersonal experiences of people living with dementia, and those who cared for or supported them
R	Research type	Original primary qualitative research

TABLE 3 Keywords/Search terms

Keywords/Search terms
1. Dementia
2. Alzheimer's
3. Memory
4. Cog*/nit/ive or tion
5. Inter/Subject/ivity
6. Interpersonal
7. Relation*/al
8. Car*
9. Nurs*
10. OR 1, 2, 3 & 4
11. + AND 5, 6, 7

3.1 | Stage 1. Getting started

At the initial stage of the review, search terms were considered and developed to find suitable and relevant articles. This began with the development of keywords. To aid this, the SPIDER search framework was used (Cooke, Smith, & Booth, 2012) as shown below in Table 2. SPIDER was useful in that it is predominately used for qualitative study searches and is considered more effective and sensitive for guiding qualitative literature reviews than alternative tools such as PICO (Methley, Campbell, Chew-Graham, McNally, & Cheraghi-Sohi, 2014).

3.2 | Search terms

Search terms selected for the primary and secondary electronic search were as follows: Dementia, Alzheimer's, Memory, Cognition, Intersubjectivity, Interpersonal and Relational, Care/r and Nurse (Including combinations and/or/not using Boolean Operator and phrases and wildcard and truncation symbols (*) shown in Table 3).

3.3 | Identification of studies

A primary full electronic search was performed on Primo Central Index = MEDLINE/PubMed, Taylor & Francis Online, ProQuest

Business Collection, Scopus (Elsevier), OneFile (GALE), Social Sciences Citation Index (Web of Science), ScienceDirect Journals (Elsevier), Cambridge Journals (Cambridge University Press), Oxford Journals, (Oxford University Press), Springer Link, Wiley Online Library, Sage publications (Sage Journals) and Emerald Insight. Citation searches and reference chaining were also completed on all relevant papers.

3.4 | Grey literature

A secondary electronic search sought literature from Alzheimer's Society, Dementia Journals/websites and Department of Health.

3.5 | Stage 2. Deciding what is relevant to the initial interest

This stage was used to focus the study by the selection of relevant studies and included a PRISMA flow chart (Figure 1) (Moher, Liberati, Tetzlaff, & Altman, 2009) and the development of inclusion and exclusion criteria. These included only English written papers and excluded studies pre-year 2000. A primary scanning search was completed, and very few numbers of studies were found on the subject of intersubjectivity in dementia pre-2000 that were relevant to the meta-ethnography.

3.6 | Selection of studies

Studies were screened according to Table 4—inclusion and exclusion criteria. Dementia was defined as any known dementia diagnosis but did not include any cognitive impairment from other causes, such as acquired brain injuries, stroke (without further decline), learning disability or any reversible cause for cognitive decline. Intersubjectivity was determined by any inter-relational or interpersonal connection between any person/people with a dementia diagnosis and another who was providing care or support to the individual/s.

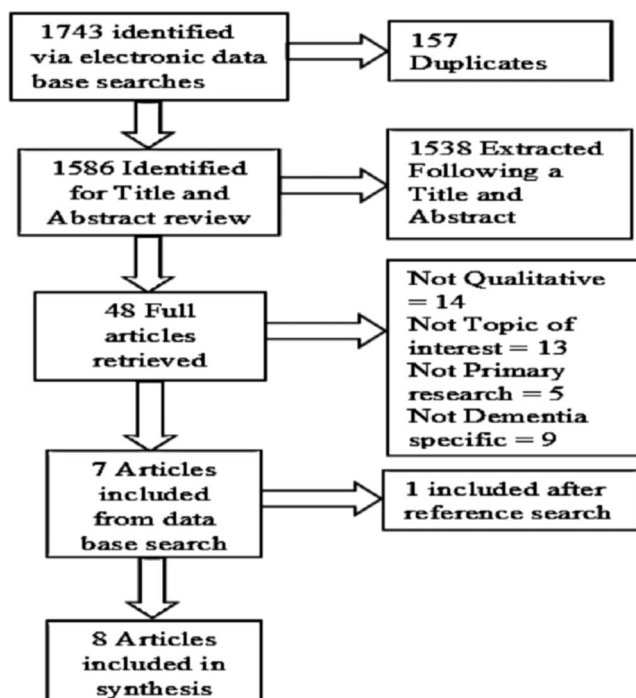
3.7 | Search findings

Once repeat studies were removed, the combined collection of database searches resulted in 1586 papers being identified. These were

TABLE 4 Meta-ethnography inclusion/exclusion criteria

Inclusion criteria	Exclusion criteria
Original qualitative research	Quantitative or mixed methodology research (unless there are substantial qualitative findings)
English-language written Journals	Nonresearch articles (e.g. opinion pieces, editorials, policy papers)
People with a dementia diagnosis/nurse/s/ carer/s (including informal/formal care providers) of people living with dementia	Non-English written papers
Intersubjectivity/subjectivity/interpersonal/ relational aspects of intervention/engagement explored in the study	Other non-dementia cognitive impairment No discussion of intersubjectivity/ interpersonal/relational aspects
Post-year 2000	Pre-year 2000

screened through a process of title and abstract review, leaving 48 articles which were shortlisted for a full content review; seven studies were selected. At this stage, a reference list review and citation chaining were completed adding one more paper, providing eight studies which met all of the inclusion and exclusion criteria. These findings are presented in Figure 1 by using a PRISMA-guided flow diagram (Moher et al., 2009). The eight selected studies were reviewed for quality and relevance for the planned meta-ethnographic synthesis which sought to explore the presence of, and factors associated with, intersubjectivity for people living with dementia.

**FIGURE 1** PRISMA flow diagram of search results

3.8 | Quality assessment

Each of the studies included in the meta-ethnography was assessed using the Critical Appraisal Skills Programme (CASP) (CASP, 2018) to evaluate the clarity, design, methodology, rigour and reflexivity of the studies (Table 5). This tool records if criteria are met (satisfied), not met (not satisfied) or is not clear by recording a tick, cross or not clear (N/C) symbol against the study for each of the 10 criteria. This provided a quick and easy read version of the tool that indicated the evaluated quality at a glance. Harrison, Reid, Quinn, and Shenkin (2016) argue that the strength and appropriateness of the quality tool are its relation to the clinical practice in question and its ease of understanding. However, the most important requirement was that the findings were relevant to the overall synthesis (Tong, Flemming, McInnes, Oliver, & Craig, 2012) and therefore could add clarity to exploration and conceptual development of intersubjectivity in dementia.

All eight studies included in the CASP evaluation were not only relevant, but also valuable to answering the literature review aims (Paudyal et al., 2018). Toye and colleagues (2016) argue strongly with studies only being included in meta-ethnography on their theoretical strength alone, noting, however, the difficulty in drawing a line of what is, or is not, methodologically strong. This meta-ethnography review did not aim to eliminate studies based on their methodological weaknesses, but instead sought their strengths of findings. There is no evidence to indicate that focusing on weaknesses in selected studies improves the quality or that seeking strengths distorts the literature synthesis findings (Campbell et al., 2011).

3.9 | Characteristics of all included studies

Table 6 presents the main characteristics of the eight included studies. Three studies were completed in the United Kingdom, two in Australia and the others across Europe. All the studies had small sample groups, ranging from 2–42, with a sample collective of 141. All participants either had dementia, cared for someone with dementia, or had contact with people living with dementia through employment or voluntary work. As the

TABLE 5 Summary of the CASP critical appraisal criteria and results

CASP critical appraisal criteria										
1. Was there a clear statement of the aims of the research?										
2. Is a qualitative methodology appropriate?										
3. Was the research design appropriate to address the aims of the research?										
4. Was the recruitment strategy appropriate to the aims of the research?										
5. Were the data collected in a way that addressed the research issue?										
6. Has the relationship between researcher and participants been adequately considered?										
7. Have ethical issues been taken into consideration?										
8. Was the data analysis sufficiently rigorous?										
9. Is there a clear statement of findings?										
10. Is the research valuable to clinical practice?										
CASP critical appraisal results										
Study	1	2	3	4	5	6	7	8	9	10
Kalis et al. (2005)	✓	✓	✓	✓	✓	N/C	✓	✓	✓	✓
Kelly (2008)	N/C	✓	✓	✓	✓	×	✓	×	✓	✓
Svanstrom et al. (2013)	✓	✓	✓	✓	✓	×	✓	✓	✓	✓
Ullán et al. (2013)	✓	✓	✓	✓	✓	N/C	✓	✓	✓	✓
Boyle and Warren (2015)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Johnson (2016)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Boyle (2017)	N/C	✓	✓	✓	✓	N/C	✓	✓	✓	✓
Marsh et al. (2018)	✓	✓	✓	✓	✓	✓	✓	N/C	✓	✓

Note: ✓, satisfied; ×, not satisfied; N/C, not clear.

meta-ethnographic synthesis focused on the presence of, and factors associated with, intersubjectivity for people living with dementia, making connections between these aims and the studies chosen was imperative.

The impact of dementia experienced by the people within the chosen studies ranged from mild to severe, and all types of dementia were included. Some of the studies lacked detail on their participant/sample demographics, so a conclusive comment on age and gender mix could not be made. However, in seven studies those diagnosed with dementia were aged between their sixties and their nineties. The exception was Kelly (2008) where the two participants had a diagnosis of AIDS dementia and were younger. Across studies, females were slightly more represented than males, particularly participants diagnosed with dementia which was the largest cohort across the studies.

All studies were qualitative in nature, seven of the eight used interviews as a main data collection method, the eighth used a focus group to seek participant perspectives. Six of the eight studies observed participants, somewhat guided by their methodology, ethnography, grounded theory and participatory research.

4 | DATA ANALYSIS

Analysis was completed using stage three to seven of Noblit and Hare's (1988) seven stages of a meta-ethnographic synthesis of

qualitative studies, as shown in Table 1 and as described in the stages 3–7 below.

4.1 | Stage 3. Reading the studies

Once the studies were selected, they were read and reread several times. Studies were read in both hard and electronic copies, and then, characteristics were extracted. Once extracted, the data were transferred to a table (Table 6). Initial themes, quotes and findings were also highlighted during this stage to begin the process of first-order construct development (Table 7).

4.2 | Stage 4. Determining how the studies are related

By using information found in the studies during stage 3 and continuing into stage 4, participant quotes were identified and highlighted where there was a connection between the intersubjective/subjective/relational/personal experiences of people living with dementia and those who cared for or supported them. These findings are shown in the first-order constructs (see Table 7 column 1). The quotes are taken directly from the eight selected studies and are the words of the study participants. The studies in which they are found are numbered next to the quote. At this

TABLE 6 Characteristics of all eight selected studies

First Author	Kalis et al. (2005) (1)	Kelly (2008) (2)	Svanström et al. (2013) (3)	Ullán et al. (2013) (4)
Country of Study	The Netherlands	Australia	Sweden	Spain
Setting	Dementia care wards	Residential care	Nursing care	Day centre Art workshop
Sample	10 participants (nursing home care staff)	2 participants (living with dementia)	25 participants (mixed people living with dementia/spouse)	21 participants (living with dementia)
Dementia type	Varied dementia types and varied stages	AIDS dementia	Varied dementia types and varied stages	Varied dementia types—mild–moderate stage
Methodology	Grounded theory	Ethnography	Hermeneutic	Exploratory study
Data collection	Observation and interviews	Observation, interview and other media (drawing)	Phenomenological interviews	Participant observation/ focus group
Role of Intersubjectivity/ Subjectivity	Professional carer experiences of quality of life for the people they care for, including the role of subjectivity	The role of memory on intersubjectivity/ subjectivity	The role of intersubjectivity in the provision of care/nursing	The move from pathology-based care to person-centred care using intersubjectivity/ subjectivity
First author	Boyle and Warren (2015) (5)	Johnson (2016) (6)	Boyle (2017) -(7)	Marsh et al. (2018) -(8)
Country of Study	UK	UK	UK	Australia
Setting	Home/local community	Care homes and community groups	Home visits	Community gardens
Sample	42 participants (21 living with dementia 21 spouses)	6 participants (living with dementia)	16 participants (living with dementia)	19 participants (4 living with dementia and 15 staff/volunteers)
Dementia Type	Varied dementia types—mild–severe	Varied dementia types—moderate	Varied dementia types—mild–moderate stage	Varied dementia types and varied stages
Methodology	Ethnography and creativity	Interpretative phenomenology	Ethnography	Participatory research
Data collection	Observation and interviews	Interviews and performative (art) social science	Observation and interviews	Observation, video and interview
Role of intersubjectivity/ subjectivity	Can intersubjectivity remain preserved in relationships when social skills are diminished	The role of intersubjectivity in the construction of identity in dementia	Can people living with dementia understand their relational self (intersubjectivity) as well as their subjective self	Can community garden/open space activity foster an active citizenship and develop relational intersubjectivity

early stage, it was noted that all eight studies provided first-order construct quotes which were relevant to the assembly of a meta-ethnographic synthesis. A relationship was beginning to emerge between all of the studies. Each stage of this process will be discussed further in this section.

5 | RESULTS

5.1 | Stage 5. Translating the studies into one another

At this stage, it was determined that the eight studies included in the synthesis had produced reciprocal (similar) results. These are represented

as five second-order constructs (see Table 7 column 2). These second-order constructs were activity in dementia, relationships in dementia, connecting with people and personhood in dementia, communication in dementia and reflexivity in dementia. The constructs were developed from the eight selected studies and are representative of second-order key terms/words used by the authors in their articles. The second-order key terms/words are shown in brackets in Table 7 column 2 under each of the five second-order constructs.

5.2 | Stage 6. Synthesising translations

All the study findings were read and reread to make sure that no data were missed, and all first- and second-order constructs were

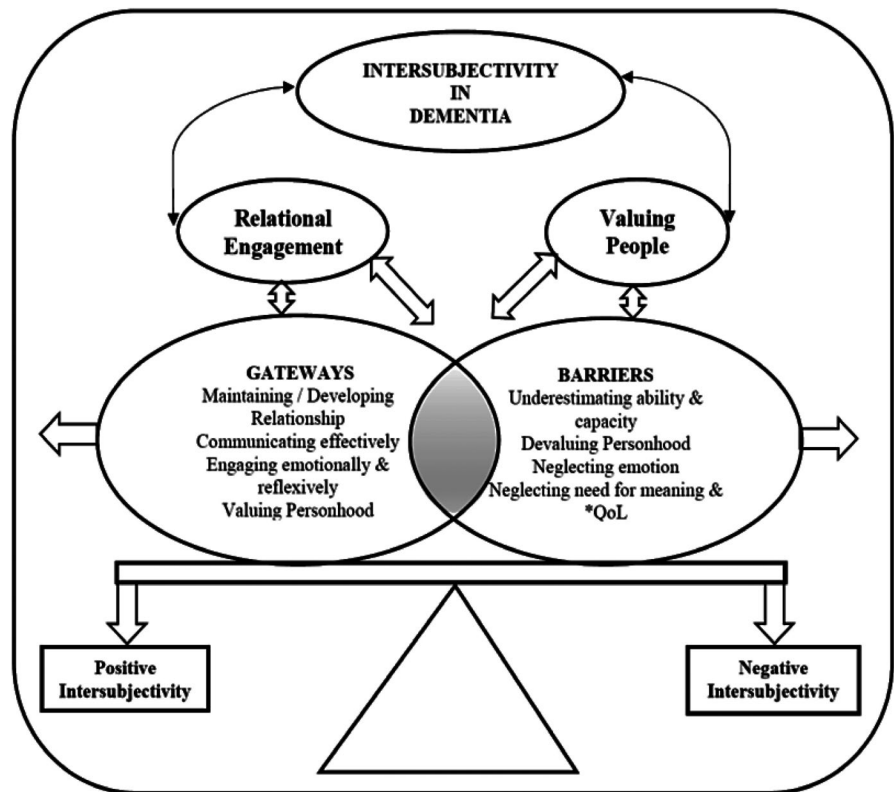
TABLE 7 First-, second- and third-order constructs taken from eight selected studies

First-order constructs (illustrative quotes) * Q = Quote	Second-order constructs	Third-order constructs
*Q1: "He is very happy sitting here... he doesn't want to go out, no." (Boyle & Warren, 2015 p.8) (Study 5)	Activity in dementia (3, 4, 6, 7 and 8)	Undervaluing the potential of people living with dementia = negative intersubjectivity
Q2: The skills of people living with dementia are frequently underestimated... "it's always good to learn"; "I didn't expect to learn"; "I have really enjoyed it, each day we learned something" (Ullán et al., 2013 p.16) (Study 4)	(meaningful activity, assuming capacity/ability, underestimating, risk vs. benefit, social roles, community, choice, quality of life, independence)	Relational engagement with people living with dementia = positive intersubjectivity
Q3: "This is a nice safe space where they can be active, where they can do things they're probably really used to doing and be part of a conversation, part of an activity" (Marsh et al., 2018 p.176) (Study 8)	Relationships in dementia (1, 2, 3, 4, 5, 6, 7 and 8) (meaningful, loving, social/gender roles, emotional, community, dis/trust, support, giving, belonging, othering, loneliness)	
Q4: "It was individual... all the workshops were individual, the people did what they really wanted to do or said they wanted to do" (Ullán et al., 2013 p.17) (Study 4)	Connecting with people and personhood in dementia (1, 3, 4, 5, 6, 7 and 8)	
Q5: "We try to maintain and guarantee the physical freedom of movement of people... we are also willing to take certain risks in that, the risk that people fall as well." (Kalis et al., 2005 p.39) (Study 1)	(de/valuing, emotion, caring, supporting, guiding, neglecting, dismissing, meeting need, recognising strength, humanity, inclusivity)	
Q6: Referring to relationships... "It's always different. You lose quite a lot when you've got dementia." (Kelly, 2008 p. 456) (Study 2)	Communication in dementia (1, 2, 3, 4, 5, 6, 7 and 8)	
Q7: "We love each other, don't we?" ... whereupon he affirmed: "Course we do." (Boyle & Warren, 2015 p.9) (Study 5)	(Listening, talking, hearing, understanding, sharing, humour, engaging, struggling, helping)	
Q8: "when I love him, I love him; when I don't love him, I like him and when I don't like him, I love him." (Boyle, 2017 p.3) (Study 7)	Reflexivity in dementia (1,2, 3, 4, 5, 6, 7 and 8)	
Q9: "... sitting there alone, you know, day in and day out, there is something terrible. I've never been alone all my life... I don't want not be a part of it anymore... my life can end now... it is enough now..." (Svanström et al., 2013 p.5) (Study 3)	(Emotional, relationships, others, caring, feeling, connection, giving, sharing, understanding)	
Q10: "I don't like being lonely. I don't like that, because you sit and think." (Johnson, 2016 p.75) (Study 6)		
Q11: "If someone could just sit with somebody in the garden what an ideal opportunity and environment to do that and just listen, that's all you have to do" (Marsh et al., 2018 p.176) -(Study 8)		
Q12: "If you've got a disease or something wrong, [people] shun you." - referring to dementia (Johnson, 2016 p.705) (Study 6).		
Q13: "we... try to connect to the feelings that people have... you estimate the feelings people have and what they need emotionally." (Kalis et al., 2005 p.39) (Study 1)		
Q14: "They will never sit down like this and talk to me; instead, they are running in and out and... and vacuuming and cleaning" (Svanström et al., 2013 p.6) (Study 3)		
Q15: Feeling valued, having meaningful roles, a feeling of belonging and contributing positively alongside others in the community... "I think it's a sense of engaging in the community ... They love it" (Marsh et al., 2018, p.176 & 178) (Study 8)		
Q16: "it's my own language that not everyone understands" (Ullán et al., 2013 p.17) (Study 4)		
Q17: "I can get through to people if I say what I want... but some of them come up to me (and say) so-and-so and so-and-so-and-so. That confuses me a bit..." (Johnson, 2016 p.704) (Study 6)		
Q18: "I'm sorry, I'm sorry... I never stop talking because I'm afraid I'll forget how to talk. Sometimes I wish my tongue was cut off so I had an excuse not to speak." (Kelly, 2008 p. 457) (Study 2)		
Q19: "They joke with me to make me happy. They listen to me and make jokes with me and then you feel as you really are a human being." (Svanström et al., 2013 p.6) (Study 3)		
Q20: Her sociable nature was evident during the fieldwork as she was very chatty and cheerful... she commented: "Yes it is, yes it is the connection, the connection through the eyes" (Svanström et al., 2013 p.6) (Study 3)		
Q21: "I like people. I love people." (Boyle & Warren, 2015 p.8) (Study 7)		
Q22: "I only like people that I like to know that they're kind, and that they're kind to other people." (Boyle & Warren, 2015 p.9) (Study 5)		
Q23: "We like to go out together. And I feel safer, because sometimes I get lost ... And I felt like a little boy, 'I want me mummy!' ... a man of six foot and I was, I was nearly crying." (Boyle, 2017 p.5) (Study 7)		
Q24: "I think my boys make me happy when they feel like it. Sometimes they make me sad, like at the moment they're not visiting me at all." (Johnson, 2016 p.705) (Study 6)		

reviewed. All studies with reciprocal findings were recorded against the second-order constructs. This was displayed by using the study identification numbers (Table 7 column 2) which openly indicate the reciprocity found across the selected eight studies. These key

findings (first- and second-order constructs) were then translated into third-order constructs. The two "found" third-order constructs ("Undervaluing the potential of people living with dementia equals negative intersubjectivity" and "Relational engagement with people

FIGURE 2 Line-of-argument conceptual intersubjective dementia care model. *Quality of Life



living with dementia equals positive Intersubjectivity”) represent both positive and negative intersubjectivity experiences in dementia care.

5.3 | Reciprocal findings

Once data were analysed and synthesis began, the eight studies displayed an ability to translate into one other, allowing reciprocal findings to emerge. The findings suggest that although people live within their own belief systems and relational rules, “the relation between the two depends upon one fact; that the individual and the society are mutually dependent, one grows with the help of the other” (Hossain & Ali, 2014 p.130). The studies did, however, represent behaviours and beliefs which are likely to impact on intersubjectivity in dementia care. These intersubjective experiences are displayed in the first- and second-order constructs (Table 7) and also the barriers and gateways to intersubjectivity in the line-of-argument synthesis and conceptual model (Figure 2). The third-order constructs developed and translated by the process of synthesis will be considered in the following section. First-order construct quotes and second-order key words will be used to represent the reciprocal nature of the findings and also offer a reference source for the reader.

5.4 | Third-order constructs

A third-order construct combines the participants’ voices and the researcher/s interpretations to offer a new theory around a specific phenomenon through a reviewer synthesises (Lachal et al., 2017).

For this meta-ethnography, the phenomenon addressed was the ability for people living with dementia to remain intersubjective, and if so, how would it present and be nurtured. These third-order constructs (“Undervaluing the potential of people living with dementia equals negative intersubjectivity” and “Relational engagement with people living with dementia equals positive intersubjectivity”) are presented below, indicating the links and synthesis between the participants’ voices (first-order constructs) which are displayed as quotes (Q-numerical). Second-order constructs/interpretations/key words will be displayed in *italics*.

5.5 | Undervaluing the potential of people living with dementia equals negative intersubjectivity

Person-centred and respectful *care* in dementia has a huge implication on the intersubjective responses care providers, or *loved* ones, may receive from a person living with dementia (Q11 and 15). This is likely to be negative if their ability to interact and *engage* is dismissed without question or reason (Q12 and Q14). Due to the nature of dementia, people with a diagnosis will potentially have difficulty with *communication*, either expressing or *understanding* (Q16 and Q18) (Kelly, 2008; Ullán et al., 2013). Not recognising or *supporting* the person to *communicate* their wants and needs will not aid *relational engagement* and may well leave the person vulnerable and frightened (Q23). This form of *neglectful* behaviour can create a divide between the person living with dementia and their care provider, which is unnecessary and unhelpful (Q17). *Relationships* on an emotional level are always important in dementia (Q6, Q22

and Q24), and if *communication* is restricted, then emotional *engagement* is even more important (Q13, Q20 and Q21).

5.6 | Relational engagement with people living with dementia equals positive intersubjectivity

Relationships as a whole are a key component of intersubjectivity and as with any form of *relationship communication* can open up the opportunity to share *feelings* and thoughts, which may otherwise go unsaid (Q7, Q8 and Q23). Without *relationships*, many people living with dementia become *lonely and isolated* (Q10) and have a *feeling* of worthlessness (Q9), with no *meaning* to their lives. This does not need to be the case as many people living with dementia can *engage* in fun (Q19), person-centred (Q4) and *meaningful* (Q3) activity which allows the person living with dementia to continue to be part of the *community* to which they *belong* (Q15). Often others feel they are doing what is best for the person living with dementia (Q1). However, by doing so, they can restrict them of their freedom in fear of reprisal (Q5). This limits their capacity to embrace new challenges and activities (Q2), which is often diminished when someone is diagnosed with dementia.

The approach of care providers towards people living with dementia was indicative within the meta-ethnography findings. The findings noted that people living with dementia are often dismissed as unable or unwilling to *engage* with *others* (Johnson, 2016; Marsh, Courtney-Pratt, & Campbell, 2018) by those who provide their care, including nurses. The quotes below have been taken from some of the eight selected and synthesised studies. They offer suggestions of how care providers and nurses can develop and maintain more *inclusive* and constructive intersubjective practices in dementia care;

Viewing reflexivity as a socio-emotional (rather than a cognitive) process enables the agency of cognitively disabled people to be more readily recognised (Boyle, 2017 p.6).

Relationships between participants were characterised by a willingness to be respectful and by intentions to include and be included, rather than by prescribed professional or volunteer roles (Marsh et al., 2018 p.177).

we... try to connect to the feelings that people have... you estimate the feelings people have and what they need emotionally (Kalis, Schermer, & Van Delden, 2005 p.39).

Feeling valued, having meaningful roles, a feeling of belonging and contributing positively alongside others in the community. A meaningful existence is core to a sense of citizenship (Marsh et al., 2018 p.178).

6 | DISCUSSION

6.1 | Stage 7. Expressing the synthesis

After all other stages were complete, and first-, second- and the third-order constructs were developed and reconsidered, the synthesis of findings allowed for a new level of interpretation to be achieved. This is represented as a line-of-argument synthesis (Figure 2) which is depicted as a conceptual model of intersubjectivity in dementia care. The model considers the barriers, gateways and the subsequent balance required to achieve positive relational and intersubjective care experiences.

The eight studies reviewed, analysed and synthesised concluded that the ability to be intersubjective remains for people living with dementia. However, intersubjectivity can only be present "If the person with dementia is respected as being "still there" (personhood) which includes the recognition that they are able to express feelings about their relationship (personness)" (England, 2017 p. 964). The review and synthesis of the studies display the capacity for intersubjectivity to take place between both parties if the key concepts found are met (achieving meaningful activity, relational connections made by valuing personhood, being reflexive and observing reflexivity and communicating effectively). All of these require the person/nurse providing care to the person living with dementia to recognise their ability to communicate and connect on a positive emotional (and at times cognitive) level, through the valuing and honouring of the person living with dementia's personhood.

6.2 | Strength and limitations

The meta-ethnography has demonstrated that it was an appropriate qualitative method of reviewing and synthesising literature to answer if people living with dementia can be intersubjective and how that intersubjectivity can be nurtured positively by those providing their care, especially, as it used established, structured and transparent processes and tools to do so (7 stages of meta-ethnography, PRISMA and CASP). The process of a meta-ethnographical literature review and synthesis has the benefit of being "greater than the sum of its parts" (Barnett-Page & Thomas, 2009 p.2).

In terms of limitations of the synthesis, there were only a limited number of studies identified in the searches to be reviewed and synthesised (8) (Campbell et al., 2011). However, Noblit and Hare (1988) recommended the review and synthesis of between 2–6 core studies in their meta-ethnography seminal text (Toye et al., 2014), which has been exceeded. To find more studies, a wider search date window could have been considered; however, the aim of this meta-ethnography review was to achieve quality and relevance within the synthesis, rather than be distracted by the quantity of studies selected (Toye et al., 2014).

7 | CONCLUSION

The meta-ethnography synthesis concludes from the reviewed literature that people living with dementia continue to have the capacity to be intersubjective on an emotional level, if not always on a cognitive level (Boyle & Warren, 2015; Kalis et al., 2005; Marsh et al., 2018). Nevertheless, intersubjectivity by its very name and process is not just one way (Boyle & Warren, 2015) and requires other to engage (Marsh et al., 2018). The findings indicate that it is of great importance that care providers, and those supporting people living with dementia, recognise that their own responses and behaviours towards a person living with dementia may influence the intersubjective outcome. The line-of-argument synthesis indicates that the person living with dementia may struggle at times with instructions and communication, and yet will still be able to intersubjectively engage with emotions even in the latter stages of dementia.

The fact that the person living with dementia will actively embrace value-based practice affords the care provider with a guide on how to achieve positive intersubjectivity. And, in doing so, it will in turn support the person living with dementia to be part of a meaningful community. It is noted that the review findings are not exhaustive but it is evident that providing positive intersubjectivity in care has positive benefits to not only to those living with dementia but also their care providers. Nevertheless, stories of poor care, neglect and mistreatment continue to emerge within dementia care provision. This perhaps emphasises a lack of investment of time and effort from some care providers and health services into person-centred forms of care that value the importance of relationships and personhood for people living with dementia.

8 | RELEVANCE TO CLINICAL PRACTICE

The constructs and line-of-argument conceptual model developed from the literature review and synthesis align with Tom Kitwood's (1997) person-centred dementia care model, and the clash, or indeed balance between malignant social psychology and positive person work in dementia. As Tom Kitwood (1990) reported, and the synthesis indicates, achieving a balance between the barriers and gateways of relationality will lead to the potential of a more positive intersubjective and caring relationship. This in turn "opens up the way for a more personal and optimistic view of care giving" in nursing to emerge, where personhood is valued (Kitwood, 1990, p. 177). The findings indicate that almost three decades on, there is still a need for those caring for people living with dementia, including nurses, to look deep inside themselves and reflect on their own actions and behaviours. This is particularly captured in a quote from Svanström, Sundler, Berglund, and Westin (2013):

In human existence, suffering is related to life itself or to different diseases that at times cannot be avoided, but when it comes to suffering related to care, the question of how this kind of suffering can be avoided remains (Svanström et al., 2013 p.2).

The ability to reflect and self-inquire in and on action (Edwards, 2017) may go some way to answer the question of whether they as care providers are a gateway, or indeed a barrier, to positive intersubjectivity in dementia care.

CONFLICT OF INTEREST

The authors have no conflict of interest or funding to declare.

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